



# **THE NATIONAL DIGITAL STEWARDSHIP RESIDENCY AT NLM**

## **PROJECT SUMMARY**

MAUREEN McCORMICK HARLOW, 2013-2014 NATIONAL DIGITAL STEWARDSHIP RESIDENT

# AGENDA

NDSR@NLM: The Project

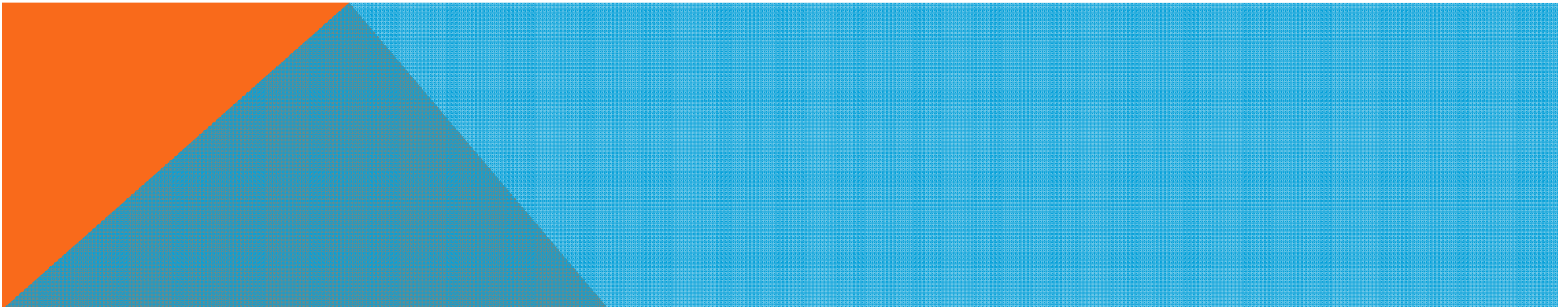
The Value of Thematic Web Collections for NLM's History of Medicine Division (HMD)

Using Thematic Collections to Fill Gaps

NDSR@NLM: The Model

NDSR@NLM: The Product

Other Activities Completed



# NDSR@NLM: THE PROJECT

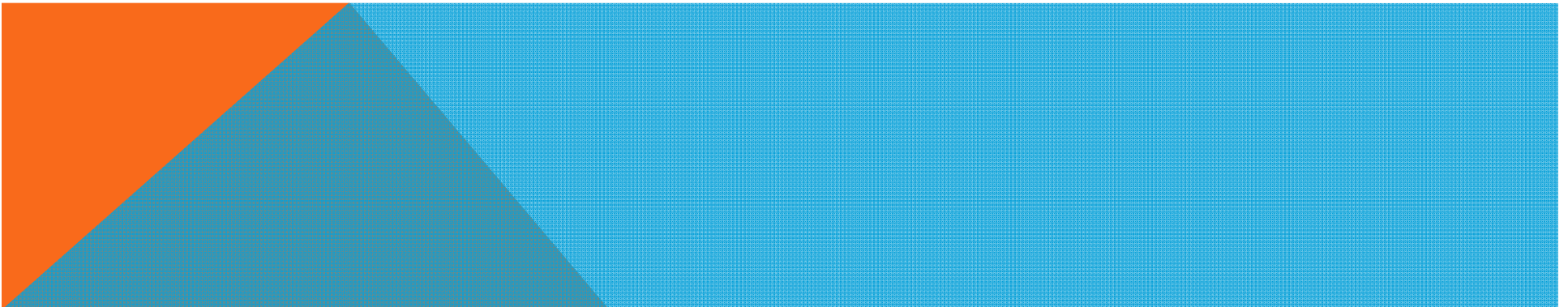
Proposed by Christie Moffatt, selected by Library of Congress

Build and Maintain a thematic Web collection:

“Disorders of the Developing and Aging Brain: Autism and Alzheimer’s on the Web”

66 Seeds evenly split, covering 6-7 perspectives:

- Current Understanding
- Caretakers (first-person resources, primarily blogs of caretakers)
- Patients/Sufferers (also first-person, also primarily blogs)
- Research
- Causes
- Treatment
- Prevention (for Alzheimer’s only)





# USING THEMATIC WEB COLLECTIONS TO FILL KNOWN COLLECTING GAPS

**U.S. National Library of Medicine**  
National Institutes of Health

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Search

Databases Find, Read, Learn Explore NLM Research at NLM NLM for You

The World's Largest Medical Library

**History of Medicine Finding Aids** History Home | About Us | Visit Us | Contact Us | Tours | FAQs | Copyright | HMD Site Map

Archives and Modern Manuscripts Program > Alpha List of Finding aids

Home Search Browse Bookbag Help Your bookbag has 0 items

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### Search Results

You searched: Archives and Modern Manuscripts Finding Aids for "autism" within Anywhere in Finding Aid, sorted by frequency  
Results: 21 matches in 3 records

1 to 3 of 3 records Sort by: frequency Sort Results

**Title: Calhoun Papers**  
**Creator:** Calhoun, John B.  
**Dates:** 1909-1996  
**Extent:** 196.27 linear feet (170 boxes + oversize)  
**Abstract:** Research data, audio and video tapes and film, photographs and negatives, charts and graphs, and reprints document Dr. Calhoun's research activity at NIMH's Section on Behavioral Systems.  
**Search Results:** 19 matches in Anywhere in Finding Aid  
search terms in context | standard view | full text File Size: 1849 K bytes | Add this to my bookbag

**Title: Bertram Brown Papers**  
**Creator:** Brown, Bertram (b. 1931)  
**Dates:** 1884-1988 (bulk 1960-1980)  
**Extent:** 65.75 linear feet  
**Abstract:** Dr. Bertram S. Brown was a key figure in the national effort to redefine and expand mental health services during the 1960s and 1970s. Dr. Brown's distinguished federal career at the National Institute of Mental Health (NIMH) helped shape many of the decisions which led to these changes. His tenure at NIMH culminated in his appointment as the Director of the National Institute of Mental Health in 1970.  
**Search Results:** 1 match in Anywhere in Finding Aid  
search terms in context | standard view | full text File Size: 631 K bytes | Add this to my bookbag

**Title: Joshua Lederberg Papers**  
**Creator:** Lederberg, Joshua  
**Dates:** 1904-2008  
**Extent:** 304.31 linear feet (309 boxes)  
**Abstract:** Lederberg (1925-2008) was winner of the 1958 Nobel Prize in Physiology or Medicine with Tatum and George W. Beadle "for his discoveries concerning genetic recombination and the organization of the genetic material of bacteria", professor of genetics at Stanford University, president of Rockefeller University, and public servant to presidents, national groups and governmental organizations.  
**Search Results:** 1 match in Anywhere in Finding Aid  
search terms in context | standard view | full text File Size: 4350 K bytes | Add this to my bookbag

# USING THEMATIC WEB COLLECTIONS TO FILL KNOWN COLLECTING GAPS



	LocatorPlus	HMD Finding Aids
Autism	951	3
Alzheimer's	1644	10

Search: alzheimer As: Keyword Anywhere -- (enclose phrases in quotes) Quick Limit: No Quick Limit Selected

25 records displayed per page Submit Reset

Previous 1 26 51 76 101 126 ... 1626 Next

search terms in context | standard view | full text File Size: 1719 K bytes | Add this to my bookbag

**Title:** Joshua Lederberg Papers

**Creator:** Lederberg, Joshua

**Dates:** 1904-2008

**Extent:** 304.31 linear feet (309 boxes)

**Abstract:**Lederberg (1925-2008) was winner of the 1958 Nobel Prize in Physiology or Medicine with Tatum and George W. Beadle "for his discoveries concerning genetic recombination and the organization of the genetic material of bacteria", professor of genetics at Stanford University, president of Rockefeller University, and public servant to presidents, national groups and governmental organizations.

**Search Results:** 8 matches in Anywhere in Finding Aid

search terms in context | standard view | full text File Size: 4350 K bytes | Add this to my bookbag

**Title:** C. Everett Koop Papers

**Creator:** Koop, C. Everett (Charles Everett), 1916-

**Dates:** 1933-2005 (bulk 1980-1998)

**Extent:** 101.25 linear feet (152 boxes)

**Abstract:**Dr. C. Everett Koop was appointed Deputy Assistant Secretary for Health, U.S. Public Health Service (PHS) in February 1981, and sworn in as Surgeon General on November 17, 1981. The collection documents Koop's career as a leading pediatric surgeon during the 1950s-1970s, his activities as Surgeon General from 1981-1989 and the many public health issues with which he was concerned, and some of his post-Surgeon General's career as a health advocate.

**Search Results:** 3 matches in Anywhere in Finding Aid

search terms in context | standard view | full text File Size: 709 K bytes | Add this to my bookbag

**Title:** Louis Sokoloff Papers

**Creator:** Sokoloff, Louis, 1921-

# THE VALUE OF THEMATIC WEB COLLECTIONS



U.S. National Library of Medicine  
National Institutes of Health

Contact NLM

Search

The World's Largest Medical Library

Databases Find, Read, Learn Explore NLM Research at NLM NLM for You

Home

Collection Development Manual

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History of Medicine

**Definition:**  
The history of medical thought and practice.

## **Scope and emphasis:**


The scope of the Library's collecting effort in the history of medicine is broad, including such topics as the history of the biological sciences; **all aspects of the practice of medicine; medical and allied professions**; histories of selected hospitals, schools of medicine, medical museums, and other health-related institutions; public health; biographies of medical figures; medicine as depicted in art, stamp and coins; **medical theories and philosophies**; popular and folk medicine; quackery; and **the sociology of medicine**. NLM also selectively acquires significant works in related subjects to document the sociocultural context of a particular era. Scholarly works are collected without regard to their language or geographical origin.

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Selected related works are acquired as needed to provide a cultural context for the study of medical history, as are the reference and bibliographical tools of historical scholarship deemed most important for the NLM mission.

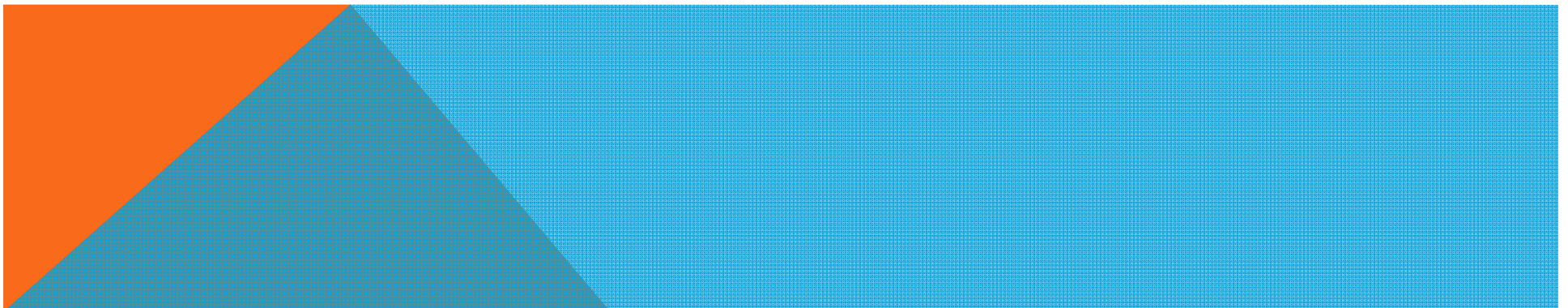


# NDSR@NLM: THE MODEL



System	Early Diagnosis	Late Diagnosis
Reproductive	Teen Pregnancy	Infertility
Musculoskeletal	Scoliosis	Osteoarthritis
Endocrine	Diabetes Type 1	Diabetes Type 2
Digestive	Eating Disorders	Obesity

The diagnoses made during an organ or system's development and decline.



# NDSR@NLM: THE PRODUCT


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The leading web archiving service  
for collecting and accessing  
cultural heritage on the web  
*Built at the Internet Archive*



[Explore](#) >> [National Library of Medicine](#) >> Disorders of the Developing and Aging Brain: Autism and Alzheimer's on the Web



## Disorders of the Developing and Aging Brain: Autism and Alzheimer's on the Web

Collected by: [National Library of Medicine](#)

Archived since: Jan, 2014

**Description:** Collection of websites crawled that represent a sample of available web resources related to Autism Spectrum Disorder and Alzheimer's Disease in 2013.

**Subject:** [Science & Health](#), [Society & Culture](#), [Blogs & Social Media](#), [Autism Spectrum Disorder](#), [Alzheimer's Disease](#)

**Creator:** [National Library of Medicine](#)

**Date:** [2013](#)

### Narrow Your Results

**Group** Sort By: [Count](#) | [\(A-Z\)](#)  
[Alzheimer's Disease \(34\)](#)  
[Autism Spectrum Disorders \(30\)](#)

**Creator** Sort By: [Count](#) | [\(A-Z\)](#)  
[Alzheimer's Association \(6\)](#)  
[Centers for Disease Control and Prevention \(4\)](#)  
[National Institute on Aging \(4\)](#)  
[United States Department of Health and Human Services \(4\)](#)  
[Autism Society \(2\)](#)  
[More ▼](#)

**Date** Sort By: [Count](#) | [\(A-Z\)](#)

Sites for this collection are listed below. Narrow your results at left, or enter a search query below to find a site, specific URL or to search the text of archived webpages.

[Sites](#) [Search Page Text](#)

Page 1 of 1 (66 Total Results)

**Sort By:** [Title \(A-Z\)](#) | [Title \(Z-A\)](#) | [URL \(A-Z\)](#) | [URL \(Z-A\)](#)

**Title:** A Diary of a Mom

**URL:** <http://adiaryofamom.wordpress.com/>

**Description:** A Diary of a Mom author Jess is a Boston-area parent with two daughters, one neurotypical and one autistic. The blog chronicles her experiences raising both children with her husband and the special challenges presented by her younger daughter's autism.

Captured 6 times between Jan 31, 2014 and Feb 4, 2014



# NDSR@NLM: THE PRODUCT

## Narrow Your Results

**Group** Sort By: **Count** (A-Z)

Alzheimer's Disease (34)  
Autism Spectrum Disorders (30)

**Creator** Sort By: **Count** (A-Z)

Alzheimer's Association (6)  
Centers for Disease Control and Prevention (4)  
National Institute on Aging (4)  
United States Department of Health and Human Services (4)  
Autism Society (2)

More ▼

**Date** Sort By: **Count** (A-Z)

English (1)

**Format** Sort By: **Count** (A-Z)

Blog (23)  
Website (22)  
Web Resource (7)  
Report (4)  
Article (popular journalism) (2)

More ▼

**Language** Sort By: **Count** (A-Z)

English (62)

Sites for this collection are listed below. Narrow your results at left, or enter a search query below to find a site, specific URL or to search the text of archived webpages.

Search

Clear

Sites

Search Page Text

Page 1 of 1 (66 Total Results)

Sort By: **Title (A-Z)** | Title (Z-A) | URL (A-Z) | URL (Z-A)

**Title:** A Diary of a Mom

**URL:** <http://adiaryofamom.wordpress.com/>

**Description:** A Diary of a Mom author Jess is a Boston-area parent with two daughters, one neurotypical and one autistic. The blog chronicles her experiences raising both children with her husband and the special challenges presented by her younger daughter's autism.

Captured 6 times between Jan 31, 2014 and Feb 4, 2014

**Group:** Autism Spectrum Disorders

**Creator:** Jess

**Language:** English

**Format:** Blog

**Title:** National Plan to Address Alzheimer's

**URL:** <http://aspe.hhs.gov/daltcp/napa/NatlPlan2013.pdf>

**Description:** Most recent update on the National Plan to Address Alzheimer's (an initiative that came out of the National Alzheimer's Project Act in 2011), including research outcomes and action items.

Captured 4 times between Jan 31, 2014 and Feb 4, 2014

**Group:** Alzheimer's Disease

**Creator:** United States Department of Health and Human Services

**Language:** English

**Format:** Report

**Title:** Autism Daddy

**URL:** <http://autism-daddy.blogspot.com/>

**Description:** Autism Daddy, an anonymous blogger, has a 10 year old son with severe, non-verbal autism. His blog provides the unique perspective of a primary caregiver father, and the caregiver to a child with severe, "classic" autism. In addition to blogging about his son, he also writes about the

# NDSR@NLM: THE PRODUCT

The screenshot shows the top of the NLM website. On the left is the NLM logo. Next to it is the text "U.S. National Library of Medicine" and "National Institutes of Health". To the right is a "Contact NLM" link and social media icons for RSS, Twitter, and Facebook. Below this is a search bar with the text "Search". Under the search bar is a navigation bar with links: "Databases", "Find, Read, Learn", "Explore NLM", "Research at NLM", and "NLM for You". Below the navigation bar is a red banner with the text "History of Medicine Finding Aids" and "Archives and Modern Manuscripts Program > Alpha List of Finding aids". Below the red banner is a yellow bar with links: "Home", "Search", "Browse", "Bookbag", and "Help". To the right of the yellow bar is the text "Your bookbag has 0 items". Below the yellow bar is a link: "< Return to search results list".

## Disorders of the Developing and Aging Brain: Autism and Alzheimer's on the Web Archive Collection 2014

full text File Size: 45 K bytes | Add this to my bookbag

Search within this finding aid:

### Title Page

### Summary Information

### Access and Use

### Biography

### Collection Scope and Content Note

### Subject Terms

### Contents List

Series I: Alzheimer's Disease Web Crawls, 2014

- Current Understanding, 2014
- Caregiver Blogs, 2014
- Patient Blogs, 2014
- Research, 2014
- Causes, 2014
- Treatment, 2014
- Prevention, 2014

Series II: Autism Spectrum Disorder Web Crawls, 2014

- Current Understanding, 2014
- Caregiver Blogs, 2014
- Patient Blogs, 2014
- Research, 2014

### Summary Information

**Title:** Disorders of the Developing and Aging Brain: Autism and Alzheimer's on the Web Archive Collection

**Creator:** National Library of Medicine (U.S.)

**Dates:** 2014

**Extent:** 66 websites (158GB)

**Abstract:**

Collection of websites crawled that represent a sample of available web resources related to Autism Spectrum Disorder and Alzheimer's Disease in 2013.

Complete web archive is available at: <https://archive-it.org/collections/4254>

**Language:** Collection materials primarily in English.

# NDSR@NLM: THE PRODUCT



Collections of the National Library of Medicine  
Search Request: Keyword Anywhere = 101631633  
Search Results: Displaying 1 of 1 records

[← Previous](#) [Next →](#)

[Summary View](#) [Detailed View](#) [Table of Contents](#) [MARC View](#) [More Like This](#)

*Disorders of the Developing and Aging Brain: Autism and Alzheimer's on the...*

Relevance: ●

Title: Disorders of the Developing and Aging Brain: Autism and Alzheimer's on the Web Archive Collection

Author(s)/Name(s): [National Library of Medicine \(U.S.\)](#)

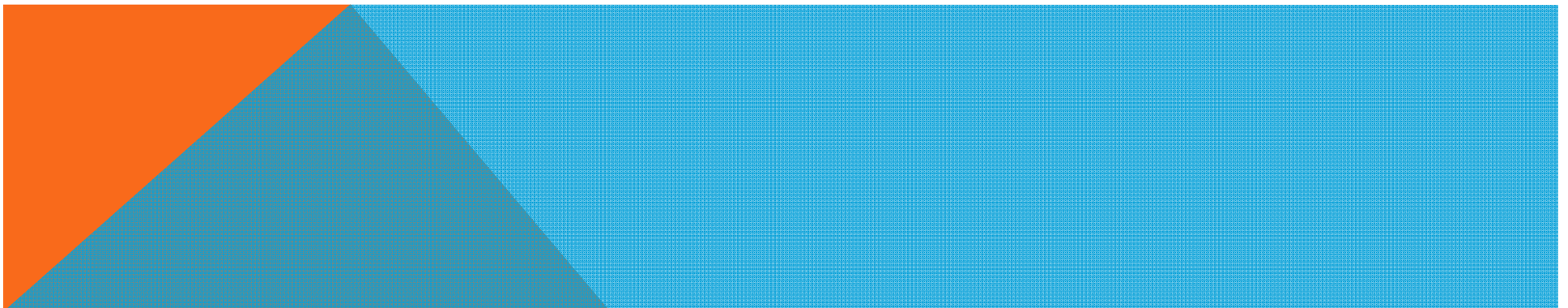
Description: 66 websites (158GB)

Electronic Links: Finding aid

<http://oculus.nlm.nih.gov/disordersweb>

<https://archive-it.org/collections/4254>

NLM Unique ID: 101631633





# NDSR@NLM: THE PRODUCT

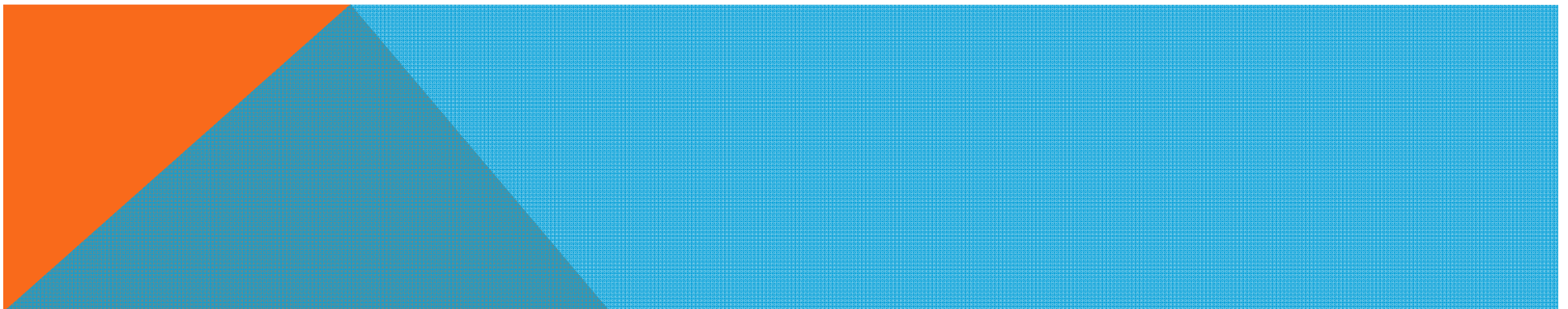
Collection finding aid live

Catalog record forthcoming

Collection represents one of the first fully curated, processed, and described thematic web collections in America

New workflows in place to routinize the proposal and collection of future web collections

Description schema put into place that can be replicated for future collections



# OTHER ACTIVITIES COMPLETED

Presented the project three times at two conferences:

- American Library Association Mid-Winter Conference, Philadelphia, PA
- IMLS WebWise Conference, Baltimore, MD

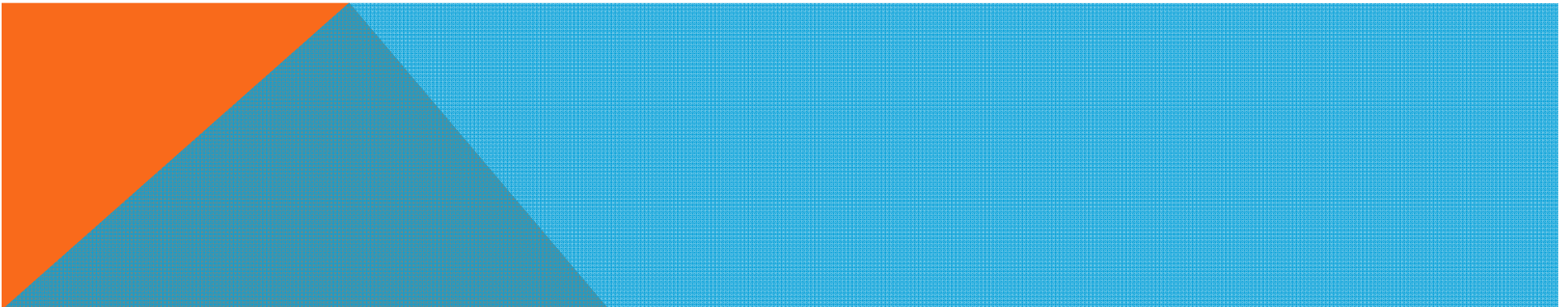
Presented the project at a DC Digital Cultural Heritage Meetup event

Attended the Tri-State Archivists Meeting (NC/SC/GA), Code4Lib pre-conference session, and Personal Digital Archiving

Scheduled to present a poster on the project at the 2014 Library of Congress NDSA meeting in July and participate in a breakout group

Coordinated a regional symposium held at NLM on April 8: Emerging Trends in Digital Stewardship

Wrote posts for Circulating Now (NLM) and The Signal (Library of Congress) blogs





# THANK YOU!

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